



# End of Life Planning

Organization  
Websites

Books

Glossary

Questions on  
Hospice

## Organization Websites

Below is a list of websites from different organizations that you may find helpful in your search for information. These websites are not all-inclusive of resources available, but are a sampling of what you might find.



### Administration on Aging

<http://www.aoa.gov>

### Alzheimer's Association

<http://www.alz.org>

### American Association of Retired Persons

<http://www.aarp.org/life/>

### American Cancer Society

<http://www.cancer.org>

### American Red Cross

<http://www.redcross.org/more/commserv/>

### Amyotrophic Lateral Sclerosis Association

<http://www.alsa.org/resources>

### Family Caregiver Alliance

<http://www.caregiver.org>

### Hospice Foundation of America

<http://www.hospicefoundation.org>

### Hospice Net

<http://www.hospicenet.org>

### Midwest Bioethics Center

<http://www.midbio.org>

### National Hospice and Palliative Care Organization

<http://www.nho.org>

*Note: This page may contain external links that are not the responsibility of, or under the control of, the Centers for Medicare & Medicaid Services (CMS). CMS does not endorse any products, services or web sites.*

## Books

Below is a list of books that you may find useful. This list is not all-inclusive, rather is a sampling of what can be found in libraries, retail establishments, and various websites.

### Dying Well: Peace and Possibilities at the End of Life

By Ira Byock, M.D.

### Handbook for Mortals: Guidance for People Facing Serious Illness

By Joanne Lynn M.D., and Joan Harrold M.D. Forward by Rosalynn Carter

### Helping Yourself Help Others: A Book for Caregivers

By Rosalynn Carter with Susan K. Golant

### Hospice Handbook: A Complete Guide

By Larry Beresford and Elizabeth Kubler-Ross

### On Death and Dying

By Elizabeth Kubler-Ross

### Quick Tips for Caregivers

By Marion Karpinski

### Share the Care: How to Organize a Group to Care for Someone who is Seriously Ill

By Cappy Capossela and Sheila Warnock

### The Family Handbook of Hospice Care

By Fairview Health Services

### The Needs of the Dying: A Guide for Bringing Hope, Comfort and Love to Life's Final Chapter

By David Kessler

### Tuesdays with Morrie

By Mitch Albom

### What Dying People want? Practical Wisdom for the End of Life

By David Kuhl M.D.

## Glossary

### Activities of Daily Living (ADLs)

Activities usually performed for oneself in the course of a normal day including bathing, dressing, grooming, eating, walking, using the telephone, taking medications, and other personal care activities.

### Area Agency on Aging

Under the Older Americans Act, the Administration on Aging distributes funds for various aging programs through state agencies on aging, which in turn fund local area agencies on aging. Area Agencies on Aging address the concerns of older Americans at the local level. They play an important role in identifying community and social service needs and assuring that social and nutritional supports are made available to older people in communities where they live. In most cases, Area Agencies on Aging do not provide direct services. Instead, they subcontract with other organizations to facilitate the provision of a full range of services for older people.

### Bereavement Counseling

Bereavement counseling consists of counseling services provided to the individual's family after the individual's death.

### Care or Case Management as defined by Case Management Society of America\*

Case management is a collaborative process which assesses, plans, implements, coordinates, monitors and evaluates options and services to meet an individual's health needs through communication and available resources to promote quality cost-effective outcomes.

### Case Manager

An individual who works with patients, families and other health care professionals to coordinate the overall medical, personal and social service needs of the patient.

### Caregiver

A generic term referring to a person, either paid or voluntary, who helps an individual with the activities of daily living, health care, financial matters, guidance, companionship and social interaction. A caregiver can provide more than one aspect of care. Most often the term refers to a family member or friend who aids the individual.

### Chore Service

Chore service is available to persons who are physically unable to perform tasks, such as heavy cleaning, minor repair or yard work, and unable to secure assistance from family or friends nor have the means to pay privately.

### Custodial Care

This term means care which is mainly for the purpose of meeting daily living requirements, such as walking, eating, bathing, dressing, and taking medicine. This is also known as "personal care" and can be provided by persons without medical skills or extensive training.

### Do Not Resuscitate Order (DNR)

Medical instructions ordering that health care providers will not take "heroic" steps to prolong the life of a chronically ill person.

### End-stage Renal Disease (ESRD)

A patient with inadequate renal function to support life. Individuals with this disease must rely on kidney dialysis or peritoneal dialysis to survive. End Stage Renal Disease may be caused by a number of problems, including diabetes, sickle cell disease, hypertension, and congenital renal disease (polycystic kidney disease).

### Guardian

An individual appointed by a court of law to manage a person's financial and/or personal affairs because the court has found that the person is not competent to manage his or her own affairs. A conservator is similarly appointed, but only for financial affairs.

### Guardianship

The process in which an individual is appointed by a court of law to manage a person's financial and/or personal affairs because the person is not able to or is not competent to manage his/her own affairs.

### Home and Community-Based Services

A variety of supportive services delivered in community settings or in an older person's home, which are designed to help older persons remain living at home and avoid institutionalization.

### Home Delivered Meals

Sometimes referred to as "meals on wheels," home delivered meals are hot and nutritious meals delivered to homebound persons who are unable to prepare their own meals and have no outside assistance.

### Hospice

Usually a combination of home and inpatient care of the terminally ill that combines medical, spiritual and psychosocial services. It is designed to help both the patient and the family. Hospice care emphasizes pain control, symptom management, and emotional support rather than life-sustaining measures.

### Medicaid

A federal/state program, established by Title XIX of the Social Security Act, that matches federal dollars to the states to provide health insurance for categories of the poor and medically indigent.

### Medicare

A federal health insurance program established by Congress for the elderly, the disabled, and individuals afflicted with End Stage Renal Disease (ESRD).

### Medigap

Medigap is designed specifically to supplement and complement Medicare's benefits by filling in some of the gaps of Medicare coverage. Medigap insurance policies are non-group policies that may pay for Medicare deductibles, prescription drugs, or other services not covered by Medicare.

### Respite Care

The provision of short-term relief (respite) to families caring for their terminally ill relatives offers tremendous potential for maintaining dependent persons in the least restrictive environment. Respite services encompass traditional home-based care, as well as adult day health, skilled nursing, home health aide and short-term institutional care. Respite can vary in time from part of a day to several weeks.

*Note: Federal and State programs may have definitions that vary, and is based on statutory or regulatory requirements. The definitions listed above (except where noted by a \*) were taken from three sources. These sources are: <http://www.aoa.gov/siteutil/glossary.asp>, <http://www.cms.hhs.gov/glossary> and the Hospice section in the new Internet Only Manual (IOM). Publication 100-02 "Benefit Policy Manual" Chapter 9, "Coverage of Hospice Services Under Hospital Insurance." This manual can be found on the web at <http://www.cms.hhs.gov/manuals>. Scroll down and click on "Internet Only Manual" and look for the Publication listed above.*

## Questions on Hospice

Below are a few web sites that have frequently asked questions and other information about hospice care. These web sites are not all-inclusive, but are a sampling of what can be found.:



- Centers for Medicare & Medicaid Services (CMS) has a publication titled "[Medicare Hospice Benefits](#)." Other Medicare publications can be found on the following website: <http://www.medicare.gov/Publications/>
- For a description of hospice, see "[What is Hospice?](#)" at the Hospice Foundation of America website (<http://www.hospicefoundation.org>). It includes a variety of meanings for the word hospice.
- Hospice Net has several frequently asked questions as well as, "[What Questions Should I ask about Hospice Care?](#)" For additional information, go to: <http://www.hospicenet.org>.

National Hospice and Palliative Care Organization's website (<http://www.nho.org>) has frequently asked questions, as well as the answer to the question, "[What is Hospice and Palliative Care?](#)"